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Original Research Article

Increasing Black Americans' participation in clinical trials: a qualitative analysis

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ABSTRACT

Background: Black Americans are underrepresented in clinical trials, a disparity that limits the applicability of medical research and perpetuates health inequities. This underrepresentation is particularly urgent given its implications for health outcomes, as it hinders the development of treatments tailored to diseases disproportionately affecting Black populations, such as hypertension, diabetes, and certain cancers. Without equitable representation in clinical trials, advancements in these areas may not fully address the unique needs of Black communities, further exacerbating existing health disparities.
Methods: This qualitative study analyzed data from four focus groups conducted in the summer of 2024 to explore perceptions of clinical trials among Black Americans. Participants, primarily over the age of 40, were recruited from diverse community settings. Deductive content analysis identified themes around knowledge gaps, attitudes, barriers, motivators, and communication strategies for healthcare providers.
Results: Results revealed a general understanding of the purpose of clinical trials. Barriers included mistrust rooted in historical injustices, logistical challenges, and perceived risks, while motivators focused on community benefits, compensation, and ease of participation. Participants emphasized the importance of clear, culturally sensitive communication and suggested leveraging a wide variety of marketing channels and community partnerships.
Conclusions: These findings will guide the development of a social marketing campaign, and a provider training curriculum aimed at increasing clinical trial participation among marginalized communities.

Keywords: Clinical trial, Clinical trial recruitment, Research participation, Research diversity

INTRODUCTION

Black Americans participate in clinical trials at significantly lower rates than white Americans, a disparity that limits the generalizability of research findings and perpetuates health inequities.[1,2] This underrepresentation is particularly urgent given its implications for health outcomes, as it hinders the development of treatments tailored to diseases disproportionately affecting Black populations, such as hypertension, diabetes, and certain cancers.[3] Without equitable representation in clinical trials, advancements in these areas may not fully address the unique needs of Black communities, further exacerbating existing health disparities. This issue is critical because the underrepresentation of Black Americans in clinical research undermines the development of treatments that are effective for all populations. The lack of diversity in clinical trials has far-reaching consequences, including

slower progress in addressing racial health disparities and Black communities.[4,5]

While some campaigns have successfully increased awareness regarding clinical trial participation, they often fall short in overcoming deeply rooted barriers such as mistrust, logistical challenges, and fears of exploitation. The gap between awareness and action underscores the need for more comprehensive strategies that address the unique concerns of Black communities while fostering trust and transparency. To further explore these challenges, we leveraged our strong reputation for community engagement to develop and complete this project with funds from our partner. Together, they aimed to investigate the perceptions of Black Americans regarding clinical trials, identify barriers and motivators, and develop strategies to improve participation rates. This study's qualitative findings will inform marketing strategies and educational initiatives to encourage participation in clinical trials, ultimately contributing to more equitable healthcare outcomes.

Our institution has contributed to engaging with and serving Black people within the Greater New Orleans region. Various initiatives led by faculty and staff from multiple disciplines ranging from biology, public health, sociology, theology, and pharmacy provide training for students to become active within the community. This has allowed students to directly interact with community members and understand how they can help reduce health barriers. Our institution holds the historical distinction of graduating the highest number of Black students who later attend medical school in the nation. By instilling knowledge of community health and engagement in its pre-medical students, we ensure that future Black physicians enter their medical education with a strong foundation in cultural competency, empathy, and social awareness.

Improving racial diversity within clinical trial participation relies on valuing the opinions and perspectives of minority communities which includes Black Americans. Historic injustices which have greatly affected Black communities contribute significantly to this mistrust. The U.S. Public Health Service Syphilis Study at Tuskegee, conducted from 1932 to 1972, remains one of the most infamous examples of unethical research practices, profoundly influencing public trust in medical research.[6-8] In this study, Black men with syphilis were deliberately misled and denied proper treatment under the guise of free healthcare, even after penicillin became the standard treatment.[6,9,10] The deception caused widespread harm, including unnecessary suffering and deaths for innocent human beings. Similar unethical studies, such as the exploitation of Henrietta Lacks, a Black woman from Baltimore whose cervical cancer cells were utilized for various scientific experiments without her consent.[11] The continued use of HeLa cells within the scientific community further highlights the importance of transparency and respect in clinical trial recruitment efforts today. Decades later, this medical mistrust remains strong in the Black community, leaving a legacy of distrust in the healthcare system that continues to shape perceptions of clinical trials among Black Americans today.[12,13] Likewise, to this present study focused on Black Louisiana residents, a study conducted in Dallas, Texas also focused on understanding the hesitancy within Black communities as it pertains to clinical trials, "But I think first and foremost, we have to acknowledge why the African-American community is reluctant to participate […] and that's because historically, African-American people have been misled, misinformed, under-informed, has sustained injury when it comes to clinical trials and studies. […] That historical knowledge carries forward."[13]

Efforts have been made to recruit more Black Americans into clinical trials, recognizing the need for diverse representation. Pharmaceutical companies like Pfizer, Gilead, and Takeda Pharmaceuticals have launched campaigns to address barriers to participation by employing specific strategies aimed at building trust and reducing logistical obstacles. These companies have turned their focus on community engagement by collaborating with trusted local organizations to host educational workshops and distributing culturally tailored informational materials. Recently, Takeda Pharmaceuticals launched a campaign focused on how psoriasis disproportionately affects both Black and Hispanic populations in terms of clinical trial participation. Takeda's approach to improving diversity in psoriasis clinical trials includes "data-driven enrollment goals, strategic site selection, and targeted recruitment strategies."[14]

Despite these efforts, participation rates among Black Americans remain disproportionately low, with recent statistics indicating that Black individuals account for only five percent (5%) of clinical trial participants, even though they represent approximately 13% of the U.S. population.[1] Additionally, a 2024 study found fundamental spiritual and religious dynamics within Black communities may also contribute to feelings of medical mistrust.[15] These disparities highlight a critical need for sustained and innovative efforts to address deep-seated mistrust, logistical hurdles, and gaps in outreach strategies that have yet to fully bridge this participation gap.

METHODS

Four in-person focus groups (n=10 to 40 participants), lasting 1.5 hours each, were conducted during the summer of 2024 at a senior center, YMCA, a neighborhood association, and a Seventh-day Adventist church. Existing community groups were identified by the project's community engagement coordinator, and focus groups were coordinated to occur during the organization's regular meetings. The only inclusion

criterion was that participants self-identified as Black American and be over the age of 18. The study was reviewed by our Institutional Review Board to ensure that ethical considerations were developed and adhered to throughout the research project. Participants provided informed consent before participating. Focus group discussions were guided by a semi-structured protocol centered around six key questions: What are the specific knowledge gaps within marginalized communities regarding clinical trials? What are the attitudes towards clinical trials among marginalized communities? What barriers prevent marginalized communities from participating in clinical trials? What motivates marginalized communities to participate in clinical trials? How can healthcare providers effectively discuss clinical trials with their marginalized patients? What are the best marketing strategies to promote clinical trials to marginalized communities?

Focus groups were recorded, and transcripts were uploaded to ATLAS.ti for analysis. The qualitative process utilized deductive content analysis, with transcripts coded by themes and subthemes. Two researchers independently reviewed the transcripts to ensure reliability and consistency in the identification of key themes. Data analysis focused on identifying patterns related to knowledge gaps, attitudes, barriers, motivators, communication strategies, and marketing approaches.

RESULTS

There were 155 participants across all focus groups with 90% of participants identifying as female and 81% identifying as African American/Black, with an average age of 69 years. Most participants (32%) were retired and 56% reported they received a high school diploma or GED. Throughout each focus group, there were participants who had previously participated in a clinical trial. The focus group discussions revealed several key themes and subthemes related to perceptions, barriers, and strategies for increasing participation in clinical trials. These findings are summarized in Table 1.

Table 1: Qualitative themes and subthemes.

Themes	Subthemes	Representative quotes/examples
Knowledge gaps	Good understanding of clinical trials	"Testing a different medication to see if it helps you" "Something to participate in to help the larger group." "They want to know the safety of the medicine they developed."
	Lack of understanding	"It's like being a guinea pig."
Attitudes	Benefits the community	"Something you participate in to help a group as a whole… It may not affect you, but it can help someone else." "Research could be beneficial… an informed opinion on how to best serve the community."
	Indifferent	"Maybe a positive, maybe a negative."
	Skeptical (Medical staff compensation)	"Pharmaceutical companies are paying doctors, nurses, and hospitals." "Doctors get paid… and if the person passes away, they say it was from an existing illness."
	Skeptical (Racial bias)	"They might do one research for the Black community, they may do another research for the white community."
	Skeptical (Lack of transparency)	"We know the good part of what is happening, but we rarely know what is actually going on…"
	Hesitant/distrust (Concern of death)	"My grandmother took pills faithfully… she got uterine cancer."
	Hesitant/Distrust (Historical unethical practices)	Tuskegee experiment
	Hesitant/Distrust (Risk factors)	"I need to know the risk factors. Do they ever tell you what they are?"
	Hesitant/Distrust (Lack of education)	"You have to educate them… they don't have trust… if you don't come out educate them, you won't have them participate."
Barriers	Side effects	"You can have something wrong… then they prescribe one medication… then side effects… then something else for that side effect."
	Logistics	Transportation; Location of appointments (long distances)
	Requirements	Too many blood draws (>4); Too many lab visits (>4); Time commitment; Lifestyle changes
	Lack of trust	Impersonal clinic team; Poor communication
	High death rate/poor outcomes	"They don't share the results from the last trial."
Motivators	Change the name from "clinical trial"	"Maybe if they try to change the name. It sounds cold and complicated."
	Compensation	Amount given to participant; What is given to the community as a whole
	Community benefits	"If the trial will service our community and fit their needs specifically… that would motivate me to participate."
	Ease of participation	"Most people got a job… you really have to make it easy for them."
	If it could benefit self or family	"If we participate today, then our generations that come after us can benefit."
	Peer support	"If somebody I know important is going to try it, I will try it too."

Continued.

Themes	Subthemes	Representative quotes/examples
Topics for healthcare providers	Information to discuss with participants	How the drug interacts with current meds; Purpose; Side effects; Long-term effects; Outcomes; Risk factors; # of participants; Expectations; Length of study; Who it will benefit; Updates on progress; Why they are a good candidate
Other considerations	Family involvement	"Include family in the decision-making…" "I don't need family coming in to say whether I should or shouldn't." "If anything happens to me, I want my family to know what I was involved in."

DISCUSSION

Overall, participants demonstrated some understanding of clinical trials, describing them as activities to "gather information and distribute it back," "study medicines or conditions," and "benefit the larger group." These responses align with the definition of clinical trials as systematic investigations to improve health outcomes.[16] A lack of basic understanding of research outcomes or purposes was noted with some participants equating clinical trials to being "like a guinea pig." This misconception reflects historical mistrust and misinformation, highlighting the need for education on the purpose and processes of clinical trials.[17]

Attitudes towards clinical trials

Many participants viewed clinical trials as beneficial for the community. Participants recognized the potential to "serve the community" and "develop informed opinions" to address health disparities. These sentiments mirror findings from previous studies emphasizing altruism as a motivator.[18,19] However, distrust emerged as a dominant theme, influenced by historical injustices like the U.S. Public Health Service Syphilis Study at Tuskegee and perceptions of racial bias. Concerns about a lack of transparency and the influence of pharmaceutical companies were also noted. A study completed in 2023 confirms how a lack of trust in the intentions of pharmaceutical companies can influence participation in clinical trials.[20] Hesitation was further fueled by personal or familial experiences with poor medical outcomes.

Barriers to participation

Participants identified several barriers to clinical trial participation, with concerns about side effects and risks being the most prominent. Many expressed fears of adverse effects and negative outcomes associated with medications tested during trials, echoing findings from prior studies.[3] Additionally, logistical challenges such as transportation, inconvenient locations for appointments, significant time commitments, and frequent blood draws or lab visits emerged as critical issues, emphasizing the need for enhanced accessibility.[21] Another major barrier was a lack of trust in clinical research, fueled by impersonal interactions with clinic staff, poor communication, and perceptions of high death rates among trial participants. This distrust, rooted in historical injustices and negative personal experiences, underscores the importance of fostering trust through culturally sensitive care and transparent communication.[12]

Motivators for participation

Participants identified several motivators for clinical trial participation, with community benefits emerging as key drivers. Many emphasized the importance of trials "bringing resources to our community" and addressing specific health needs, highlighting the value of visible, tangible benefits to their communities.[18,19] Financial compensation was also noted as a significant factor, with participants stressing the need for adequate incentives not only for individuals but also for the community at large. Altruistic ideals which motivate individual participation in clinical trials as a means of helping their community.[22] Additionally, simplifying the trial process, reducing time commitments, and providing flexible scheduling were suggested as ways to encourage participation by making the experience more accessible. The role of peer and family support also emerged as influential, as participants expressed that encouragement from trusted individuals and family involvement in decision-making played a vital role in their willingness to consider clinical trials.[3] Finally, many participants suggested that reframing clinical trials by creating a new name for the process could help alleviate the negative connotations associated with the term "clinical trial," which some felt carried historical and cultural baggage. This rebranding effort, combined with the other motivators, has the potential to increase participation rates among Black Americans significantly, which has been reported be around 5% in the United States.[23]

Effective communication by healthcare providers

Participants in this study consistently emphasized the critical need for clear communication in clinical research settings. This included a strong preference for plain language, with participants urging providers to avoid medical jargon and present information about side effects, risk factors, potential outcomes, and benefits in an easy-to-understand manner. This emphasis on clear and accessible communication aligns with existing research demonstrating its crucial role in fostering trust within clinical research.[12] Furthermore, participants highlighted the importance of culturally sensitive recruitment strategies, advocating for approaches that avoid making individuals feel targeted based on race.

Finally, regarding family involvement, participant perspectives varied: some preferred collaborative decision-making with family members, while others prioritized personal autonomy while keeping their families informed.

Implications for practice

To address concerns of community members and remove barriers to participating in clinical trials, there are several steps practitioners can take to strengthen trust and increase participation. Establishing strong partnerships with trusted organizations, such as churches, senior centers, and local nonprofits, to act as messengers for clinical trial opportunities is a vital step in connecting with community members outside of clinical settings. This step equips community leaders and influencers with informational toolkits and provide training on how to engage their members effectively.

Educational materials

Develop informational flyers, pamphlets, and videos written in plain language. Materials should prioritize key information, such as the purpose of clinical trials, safety protocols, and potential benefits to both participants and the community. Use relatable imagery and testimonials from previous participants to foster trust and relatability. Include QR codes or links to websites to simplified enrollment platforms to encourage immediate action.

Promotional tactics

To compliment the plain language educational materials, a comprehensive marketing strategy should incorporate multiple promotional tactics, a well-defined budget for advertising, and a focus on fostering trust, transparency, and accessibility. Key strategies based on focus group insights, for earned media - partner with local media outlets, such as community newspapers, radio stations, and trusted podcasts, to share success stories of participants who have benefited from clinical trials. Leverage press releases to highlight how clinical trials address diseases that disproportionately affect Black communities. Using paid media, invest in targeted digital advertising on platforms frequented by the target demographic, such as Facebook, Instagram, and YouTube. Use culturally tailored imagery and messaging, with a focus on highlighting benefits, safety protocols, and compensation. Organize health fairs, workshops, and town halls in collaboration with trusted local organizations and community leaders. These events can include presentations from healthcare professionals and past trial participants to demystify the process and address concerns in person. Promote family involvement in decision-making, as this was a key motivator noted by participants. Lastly, based on participant feedback, rename clinical trials with terms like "health studies" or "wellness research programs" to reduce negative connotations and foster a more approachable image.

Budget allocation

Allocate a balanced marketing budget to ensure sufficient investment in both paid and earned media. For example, paid Media: 50% of the budget, focusing on digital ads, video campaigns, and sponsored posts. Community Engagement: 30% of the budget for events, workshops, and materials tailored to specific local needs. Creative Development: 20% of the budget for designing engaging content and rebranding efforts. These insights will inform the development of a social marketing campaign and provider training curriculum to increase awareness and participation in clinical trials within marginalized communities.

Student trainings

In addition to the comprehensive marketing campaign, there is a need for the development and training of students and health care providers to address the barriers and attitudes community members have towards clinical trials. Data from this study will be utilized to inform the development of a training curriculum for students and health care providers that aims to address community identified barriers through hands on scenarios and interactive sessions.

Continuing education units

It may be beneficial to create continuing education units (CEUs) for health care providers to receive new trainings and opportunities to increase minority population participation in clinical trials and research. The CEUs can provide space for ideation on how to increase motivation by moving the priority group from pre-contemplation to contemplation. They can help to improve curriculum for students and health care providers to address the barriers and concerns of community members. Healthcare providers can receive new trainings on increasing minority participation in clinical trials and research. Practitioners can engage in community level medicine instead of just an individual-level medicine focus by participating in more community engagement opportunities, such as health fairs to engage community members outside of clinical settings.

CONCLUSION

Results from this study help provide intentional steps researchers and clinicians can make to ensure that patients, especially those from backgrounds that have a history of mistrusting the healthcare system, participate in clinical trials to improve their health outcomes. Specifically, the need to rebrand clinical trials to a term that community members feel is less daunting and more relatable. These steps will ensure that a larger group of people can access medications, treatments, and resources that can work to close persistent disparities gaps. Working in partnership with community health workers, academics, and community organizations can address

barriers and increase motivators to participating in clinical trial research.

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